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New Family Health History Projects Focus on Alaska Native, Appalachian Communities

Acting Surgeon General Urges Americans to Know Their Family Health Histories

Washington — As part of the effort to educate all Americans about the importance of knowing their family health histories, Acting Surgeon General Kenneth P. Moritsugu, M.D., M.P.H., today announced two new outreach projects involving Alaska Native and urban Appalachian communities.

"This Thanksgiving, we will celebrate the third annual National Family History Day. As families across the nation come together to relax and give thanks, it's an ideal time for each of us to start learning more about our family health history," Dr. Moritsugu said. "This is not just knowledge for knowledge's sake. Knowing your family health history can save your life, as well as the lives of those you love."

Many diseases, such as cancer, diabetes and heart disease, can run in families. Health care professionals can use your family health history to help predict the disorders for which you may be at risk. Such information can help health care professionals develop more individualized strategies for keeping you and your family healthy.

"Gathering your family health history really is the first step towards personalized medicine," said Francis S. Collins, M.D., Ph.D., director of the National Human Genome Research Institute (NHGRI), part of the National Institutes of Health. "We are working on technology that will enable doctors to quickly read your genome and devise personalized health strategies based on your unique genetic blueprint. But we aren't quite there yet. So, in the meantime, the best approach is to give your doctor as much information as possible about your family's health history."

To make it easier to compile a family health history, the Office of the Surgeon General has created a free, Web-based tool that organizes family health information into a printout that people can take to health care professionals to help determine whether they are at higher risk for disease. The recently redesigned tool, "My Family Health Portrait," is available in English and in Spanish at <https://familyhistory.hhs.gov>.

"My Family Health Portrait" tool is Web-based, which allows it to be operated on all computers with Internet access running any of several standard browsers, regardless of the computer's operating system. All personal information entered into the program resides on the user's computer only. No information is available to the federal government or any

other agency.

Since the Surgeon General's Family Health Initiative began in November 2004, more than 1 million users have accessed the Web-based version or downloaded copies of the "My Family Health Portrait" tool from the HHS Web site. In addition, more than 100,000 printed copies of the tool have been distributed nationwide. Department of Health and Human Service agencies that are partnering with the Surgeon General in the family history public health campaign are: NIH-NHGRI, the Centers for Disease Control and Prevention (CDC), the Health Resources and Services Administration and the Agency for Healthcare Research and Quality.

Building upon the foundation laid by the Surgeon General's Family History Initiative, NHGRI today named two new Family History demonstration projects - focused on Alaska Native and urban Appalachian populations. The one-year projects, each of which will receive \$100,000, will develop community-based models to increase awareness among the public and health care professionals about the value of family history information in promoting health and preventing disease.

In the first project, a multi-institution team will work with Appalachian populations living in the greater Cincinnati metropolitan area, which encompasses southwestern Ohio and northern Kentucky, and in the Dayton, Ohio metropolitan area. A major goal of the project is to develop ways of educating people with low levels of literacy about the importance of family health history. Another goal will be to raise awareness among health care professionals working in the targeted areas about the need to collect family health information. The team will be led by Melanie Myers, Ph.D., assistant director of the Genetic Counseling Program at the University of Cincinnati. Other collaborators include the Cincinnati Children's Hospital Medical Center, The Appalachian Outreach Studies Program at Sinclair College in Dayton, the Area Health Literacy Program at Ohio State University and six local community organizations. The community organizations are Brighton Community Center in Newport, Ky.; Lower Price Hill Community School and Urban Appalachian Council, both in Cincinnati; Life Enrichment Center, Sunrise Center Weed and Seed Initiative and Volunteers of Greater Ohio, all in Dayton.

The second project will be led by Ruth Etzel, M.D., at the Southcentral Foundation, which is an Alaska Native health care organization located in Anchorage. The primary goal of this effort will be to develop tools and methods for creating a common understanding about the role and importance of family health history among Southcentral Foundation's staff. The foundation employs more than 1,300 people, of which more than half are Alaska Natives. This project will receive co-funding from NHGRI and the NIH's National Center on Minority Health and Health Disparities.

"We are excited about the potential of these projects to expand the reach and impact of the Surgeon General's Family Health Initiative. We look forward to working with these communities to achieve their goals, as well as to sharing their models with other communities and populations across the country," said Vence Bonham, J.D., chief of NHGRI's Education and Community Involvement Branch, which administers the projects.

The new projects will expand upon what is being learned in NHGRI's Family History demonstration project at Brigham and Women's Hospital in Boston. That effort, launched in November 2005, has been encouraging and evaluating the voluntary use of the Surgeon General's "My Family Health Portrait" tool among the hospital's more than 12,000 employees. The workforce of the 747-bed hospital includes physicians, nurses, administrative, service and management staff. This month, the Brigham and Women's Family History Project is expanding to include non-employee patients and their families. The project's website, <http://www.brighamandwomens.org/familyhistory>, will post results

of the yearlong project as they become available after the conclusion of the employee survey on Nov. 30.

The CDC is funding the state health departments in Utah, Oregon, Minnesota and Michigan to incorporate genomics into their health promotion and disease prevention activities. All four states are tying activities to the Surgeon General's initiative to increase awareness about family history among health providers and the general public. This month in Michigan, the Oakwood Health Systems will distribute family history information to all of its employees during a period of open-enrollment for benefits. In addition, Oakwood will distribute bookmarks with information on the Surgeon General's family history tool with personnel paychecks and set up a booth on genomics and family history in the hospital. Oregon is launching a project with federally qualified health centers to learn about how family health history is being used by the providers in these centers.

The goal of the project is to determine what resources and technical assistance will be needed to support providers in using family history to identify patients at risk for chronic diseases and motivate them to make lifestyle changes.

The Utah genomics program has produced an award-winning multimedia project, "Make Family Health History A Tradition," to raise public awareness about the importance of family history. Utah is in a unique position to tie their efforts with their population's strong interest in genealogy. This year, the state health department is sponsoring a "Tell Us Your Story" contest that encourages families to order Utah's family history materials, learn about their family histories over holidays and submit their stories for a prize. Minnesota has developed a number of facts sheets about chronic diseases in which family history plays a major role. These fact sheets will be used this month in family history campaigns in hospitals across Minnesota and at the state health department.

Additionally, Minnesota and Michigan have begun to incorporate family history risk assessment into their WISEWOMAN programs. WISEWOMAN is a federally funded initiative to identify underserved women at risk of cardiovascular disease, counsel them about diet and exercise, and refer them for further risk factor screening and follow-up care. All of the four states are promoting "My Family Health Portrait" as an easy to use tool for organizing family health history information.

In addition to the Web-based tool, printable, PDF versions and other resources related to the Surgeon General's Family Health Initiative are available at <http://www.hhs.gov/familyhistory>. New materials for 2006 include a printable PDF brochure entitled "Before You Start" and a redesigned, user-friendly PDF version of the tool, both of which are available in English and Spanish. Other new additions include links to printable PDF versions of the tool in Chinese, Polish, Portuguese and French, which were produced by translators with the Brigham and Women's Family History project.

NHGRI is one of the 27 institutes and centers at the NIH, an agency of the Department of Health and Human Services (DHHS). Additional information about NHGRI can be found at its Web site, www.genome.gov.

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